**Special Commission to Study Pancreatic Cancer**

Meeting Minutes

March 26, 2019

3:00 -5:00 pm

**Date of meeting:** Tuesday, March 26, 2019

**Start time:** 3:02pm

**End time:** 4:58pm

**Location:** Conference Room 1, 21st Floor, One Ashburton Place, Boston, MA 02108

**Members present:**

* Joshua Nyambose—Department of Public Health
* Niels Puetthoff—Division of Insurance
* Jody Quinn—Pancreatic Cancer Action Network
* Janice Griffin—Pancreatic Cancer Action Network
* Cynthia Callahan, RN—Patient Advocate (Vice Chair)
* Brock N. Cordeiro—Patient Advocate (Chair)
* Andrea Cleghorn—Survivor
* Dr. Giles Whalen—UMass Memorial Health Care
* Representative John Mahoney—Massachusetts House of Representatives
* Brian Rosman, on behalf of Senator Jo Comerford—Massachusetts Senate
* Carole Seigel – Patient Advocate

**Members absent:**

* Dr. Brian Wolpin—Dana-Farber Cancer Institute
* Dr. Andrew Warshaw—Massachusetts General Hospital
* Lauren Peters – Executive Office of Health and Human Services
* Doug Shatford—Pancreatic Cancer Caregiver

**Proceedings:**

The Chair called the meeting to order at 3:02pm. He welcomed members to introduce themselves and their relevant affiliations. Brian Rosman, Legislative Director for Senator Jo Comerford, sat in the meeting on behalf of the Senator. Members who were not present at the first meeting who introduced themselves were: Representative John Mahoney, Joshua Nyambose, Senior Epidemiologist at the Department of Public Health (DPH), and Carole Seigel, Patient Advocate.

The Chair reviewed the meeting agenda and opened the floor to the Vice Chair to present (see meeting slide deck).

Mr. Rosman inquired as to how hospitals can achieve a National Pancreas Foundation designation. The Vice Chair described a process of application, criteria, and audits. Ms. Seigel noted that she helped to establish these standards, and that a big factor for accreditation is the presence of a “strong palliative care support program,” and highlighted that this factor is often limiting for care settings in remote locations. She mentioned current progress on a federal bill for a palliative care training act. Mr. Rosman inquired about barriers to hospitals working towards this designation; the Vice Chair explained that one criterion includes a threshold of surgical procedures per provider per year, and that the dearth of patients in more remote locations poses a limit to how many procedures a given provider could reasonably perform.

The Vice Chair speculated that many patients are traveling from out of state for their treatment, and that this population may skew the number of deaths from pancreatic cancer in the Commonwealth. She emphasized that early detection through education is key, and that identifying patients in early detection as candidates for surgery was shown to vastly increase survival rates in a Japanese study cohort. She mentioned risk factors such as family history and diabetes potentially being incorporated into screening protocols.

Ms. Seigel offered that even if hospitals in Western Massachusetts don’t have the patient volume needed to qualify for National Pancreas Foundation designation, that they could still take other steps to improve patient quality of life. The Vice Chair agreed, and noted that “even something as basic as palliative care” could make a difference, along with the establishment of certain post-surgical standards throughout the state.

Mr. Nyambose requested more detail on where the Vice Chair’s mortality information was sourced from (see slide 3). She replied that it was cited from a recent Surveillance, Epidemiology, and End Results (SEER) Program report, which she offered to circulate to members.

The Vice Chair opened the floor to a discussion on whether the Commission’s work should focus on the most common form of pancreatic cancer (pancreatic ductal adenocarcinoma, or PDAC), or to also include pancreatic neuroendocrine tumors (PNETs). She explained the difference between these forms (see slide 10). The Chair offered his opinion that the Commission take the “holistic approach” and address all forms. Ms. Griffin and Ms. Quinn agreed. Mr. Puetthoff concurred, explaining that the charge of the Commission includes ascertaining the unmet needs of pancreatic cancer, and that ignoring one form of it would perpetuate an unmet need. The Chair announced that the goal of the Commission moving forward would be to include all forms of pancreatic cancer in its work.

The Chair then opened the conversation to a discussion of the unmet needs of patients (slide 11). Ms. Quinn offered that doctor-patient communication is an area needing improvement. She expressed that without someone else in the room to “interpret the information,” many patients and families find conversations with providers overwhelming and overly-technical. The Vice Chair agreed and noted that an increasing number of pancreatic cancer programs include nurse navigators to play the role of intermediary.

Dr. Whalen arrived at 3:28pm.

Ms. Griffin raised the issue of language barriers in treatment settings. Ms. Seigel agreed and offered that she thought a mechanism for “enclaves,” to take a “cookie cutter,” approach is a potential way of getting information disseminated in areas with high density populations of speakers of a certain language. She noted that this could include information about clinical trials.

The Chair agreed and noted that clinical trials can be difficult for patients to access, even in the absence of language barriers. The Vice Chair noted that navigating clinicaltrials.gov can be complicated. Dr. Whalen noted that the National Institute for Health (NIH) website serves as another resource, but that the larger issue is that clinical trials haven’t consistently produced effective treatment for pancreatic cancer. The Vice Chair added that enrollment in pancreatic cancer clinical trials are lower than they could be, due to a lack of education around the disease. Ms. Seigel agreed, noting “a short window of opportunity” after diagnosis to enroll in a trial. Dr. Whalen noted that language barriers can arise in clinical trials in the form of IRB consent forms, which need to be translated for each patient. He highlighted “practical and financial” barriers to including all patients on trials.

Ms. Griffin inquired about whether insurance covers or supports the costs of clinical trials. The Vice Chair clarified that the sponsoring company covers costs, and Ms. Seigel noted that Massachusetts only requires insurance companies to cover the “standard of care.” Dr. Whalen explained that for most trails, there is an additional standard of care not included in the base trial costs, and that in the case of federal clinical trials, this can produce “miscommunication between arms.”

The Vice Chair summarized the story of a survivor, who received the Whipple procedure, and subsequently experienced severe gastrointestinal complications. The survivor returned to work and needed to take frequent restroom breaks, for which she was ultimately fired, even after explaining to her employer why these breaks were needed. She later found out that her cancer had returned, and she no longer had employer-sponsored benefits. The Vice Chair cited this as an example of an unmet need in the form of protections for patients who re-enter the workforce with disabilities related to their treatments. Dr. Whalen and Ms. Quinn both agreed, citing similar personal experiences.

Mr. Rosman inquired about what policy recommendations around drug costs would be possible for the Commission to make. He mentioned the Governor’s provision around upper payment limits on drugs under MassHealth, and suggested that a recommendation of the Commission could be to similarly take state-level action to control drug prices. Ms. Quinn and Ms. Seigel both agreed that drug costs are an issue of great concern.

Ms. Cleghorn described her personal experience of seeking multiple opinions after her diagnosis, and needing to speak to multiple providers in order to get adequate information about her treatment options. The Chair agreed that this was a concerning issue, that fell into the category of lack of effective doctor-patient communication.

The Chair then asked members to discuss the unmet needs of families (slide 12). Ms. Quinn noted the “psychosocial” impacts of caregiving, and differentiated the effects of pancreatic cancer on families from the effects of other cancers, given the “quick impact” it can have. Ms. Griffin noted the need for “resources in general,” ranging from information to formal caregiving support. Dr. Whalen noted that many of these concerns are not unique to pancreatic cancer.

Ms. Seigel noted the opportunity for using a telemedicine model to assemble virtual support groups for caregivers who may live in remote areas or who cannot easily leave the home due to their caregiving responsibilities. Dr. Whalen and the Vice Chair agreed that this idea was worth consideration. Ms. Seigel also noted the importance of family and caregivers for patient symptom monitoring/support. She recalled an incident where her husband had the hiccups, and after she mentioned this new symptom to his provider, he received a prescription to manage the aggravation of his esophagus; her husband would have likely not mentioned to his doctor, either because he didn’t note his hiccups as a related symptom or because he didn’t want to be “burdensome.”

Representative Mahoney left the meeting at 3:44pm.

Dr. Whalen noted that a “feature of the modern complex hospital system” is that providers are becoming hyper specialized in particular areas, sometimes at the expense of their general medical management skills, which may contribute to the kind of oversights that Ms. Seigel’s husband may have experienced had she not advocated for him. Ms. Seigel agreed, noting that a patient navigator could mitigate these trends.

The Chair mentioned the issue of a lack of public awareness and heightened stigma around pancreatic cancer. Ms. Cleghorn noted that this partially due to the “hopelessness” associated with it; Ms. Seigel agreed, pointing out that “there aren’t enough survivors to make the point.” Dr. Whalen brought up that as a research enterprise, pancreatic cancer is not an area of focus for drug manufacturers, as phase 1 and 2 trials often “die on the spear of pancreatic cancer.” He noted that this is discouraging for pharmaceutical companies, but that other cancers, such as lung cancer, were in a similar position in recent years, but new breakthroughs (such as immunotherapy) have changed those fields.

Mr. Nyambose raised the issue of financial burden of treatments and passing of patients, especially if they were primary providers for their family units. The Vice Chair agreed, noting that many organizations provide patient funding, such as providing funds for hotel stays near treatment centers, or paying a patient’s mortgage for a month, but that these resources are not widely known among patients. She also noted the lack of knowledge around genetic testing for individuals with family histories of pancreatic cancer.

Ms. Quinn raised the unmet need of respite caregiving, especially for older caregivers. The Chair agreed that this was an important unmet need. The Chair then asked that members consider these unmet needs and come to the next meeting prepared to identify potential opportunities for action.

Dr. Whalen reiterated that many of these needs are not specific to pancreatic cancer, but some are. He noted that Ms. Seigel’s idea for tele-support groups is a potential solution for a lot of people. He also noted that “increasing the vibrancy” and awareness of internet support groups is an area of potential improvement.

The Chair opened the conversation to discuss current registry information (slide 13). The Vice Chair asked Mr. Nyambose what the DPH currently collects data on. Mr. Nyambose reported that cancer stage, race, gender, and sometime insurance status and treatment information is available in DPH patient registries. He noted that those are the “basic” levels, but that further information could be gleaned and brought for the Commission’s review.

Ms. Cleghorn noted that because pancreatic cancer is so “fast-moving,” increasing awareness about risk factors and early signs is important. Ms. Quinn agreed, noting that the known symptoms are very vague.

The Vice Chair asked Mr. Nyambose whether DPH data could derive statistics about patients in the Commonwealth being diagnosed at certain stages, or dying at certain average ages. Mr. Nyambose confirmed that this is possible. The Vice Chair inquired if hospital name was a possible data point, and Mr. Nyambose explained that that information is not available. He also clarified that to the Vice Chair’s earlier point, the number of pancreatic cancer deaths in the state for individuals coming from out of state for treatment constitutes a very small portion of total deaths. Dr. Whalen explained that due to the biology of pancreatic cancer and the relative lack of effective therapy, any differences in outcomes based on treatment setting are “washed out.”

Mr. Nyambose went on to note that smoking and being overweight or obese are significant risk factors for pancreatic cancer. He suggested that a strategy of primary prevention could be formulated if the Commission can “try to connect the dots.” Dr. Whalen agreed, and noted that the largest risk factor is age. Ms. Seigel agreed for the need for more research, and noted frustration that researchers do not access all the adequate specimens that are available for study. Dr. Whalen agreed, but highlighted the high cost and large infrastructure needed to maintain tumor banks. Ms. Seigel agreed, but noted that this Commission is an opportunity to make a statement about the allocation of resources. The Vice Chair mentioned a hospital in Salt Lake City with a blanket consent form for all patients in the pancreatic cancer program to donate all possible specimens for research, noting that the Commission could recommend that the state implement a similar blanket consent form in research hospitals.

The Chair noted that the work of the Ovarian Cancer Commission was similar in approach to the work of this body, and that they tackled a few specific issues in depth. Dr. Whalen noted “three ways to think about this:” (1) to push to discover the cause of pancreatic cancer, (2) to find it early, and to focus on high risk individuals, and (3) to develop effective treatment. He suggested that it might be most effective to focus on the high risk population. The Vice Chair noted the strong increase in the risk for pancreatic cancer diagnosis after the first 3 years of a diabetes diagnosis, and suggested that screenings for new onset diabetes could also include a screening for pancreatic cancer.

The Chair noted that the Ovarian Cancer Commission had engaged the work of an outside firm (JSI) to assist. He asked members whether they would be interested, if funding were available, in looking into the possibility of a similar contract. Dr. Whalen agreed that such a contract would be reasonable, but only if the Commission were very clear on its mission and goals, and didn’t lean too heavily on an outside firm to steer the direction of its work. The Vice Chair and Ms. Quinn agreed that the Commission should continue to steer itself, in the event of such a collaboration.

The Vice Chair mentioned a 2014 proposed act for pancreatic cancer screening among high risk populations. She encouraged members to read the text of this proposed act.

**Vote: Dr. Whalen introduced a motion to accept the minutes of the February 6th meeting, which was seconded and unanimously approved.**

The Chair reiterated his request for members to come to the next meeting with more “refined” lists of unmet needs for patients and families.

**Vote: The Chair introduced a motion for the meeting to adjourn, which was seconded and unanimously approved.**

The meeting was adjourned at 4:58pm.